DOCUMENT RESUME

ED 271 274 RC 015 836

AUTHOR Helge, Doris
TITLE Prevention of Mental Retardation in Rural America.
INSTITUTION American Council on Rural Special Education.
PUB DATE Sep 84
NOTE 17p.; Document was extracted from a 1984 presentation to the President's Commission on Mental Retardation.
PUB TYPE Guides - General (050)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Change Strategies; Community Change; *Cultural Influences; Developmental Disabilities; Disadvantaged; Intervention; *Mental Retardation; *Prevention; *Rural Areas; Rural Population; Rural Urban Differences; Social Change; *Socioeconomic Influences
IDENTIFIERS American Council on Rural Special Education; National Rural Project

ABSTRACT

This paper describes causes of mental retardation in rural America, preventative methods, and factors impeding preventative approaches in rural settings and offers principles for tailoring traditional preventative methods for rural areas. Relevant findings of research conducted by the National Rural Project, American Council on Rural Special Education (ACRES), ACRES Futures Task Force, and National Rural Education Research Consortium are included. Higher poverty ratios, educational disadvantagement, inadequate prenatal care, and lack of early intervention programs for disabilities are found to contribute to the socio-familial factors that make mental retardation more prevalent in rural than in urban areas. Value differences, lack of prevention-oriented programs and failure to understand, value, or use available programs are found to inhibit prevention. Principles and suggestions for implementing retardation prevention programs in rural areas are given, including recognizing diverse rural subcultures and designing programs to consider their values and needs, recognizing and using local communication and power structures, using inherent positive community attributes, transforming negative attributes into facilitating factors, and initiating realistic interagency collaboration in rural service agencies. These principles are related to a tabular presentation of causes of mental retardation, preventive approaches, and specific rural factors which inhibit prevention. (LFL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

SCOPE OF INTEREST NOTICE

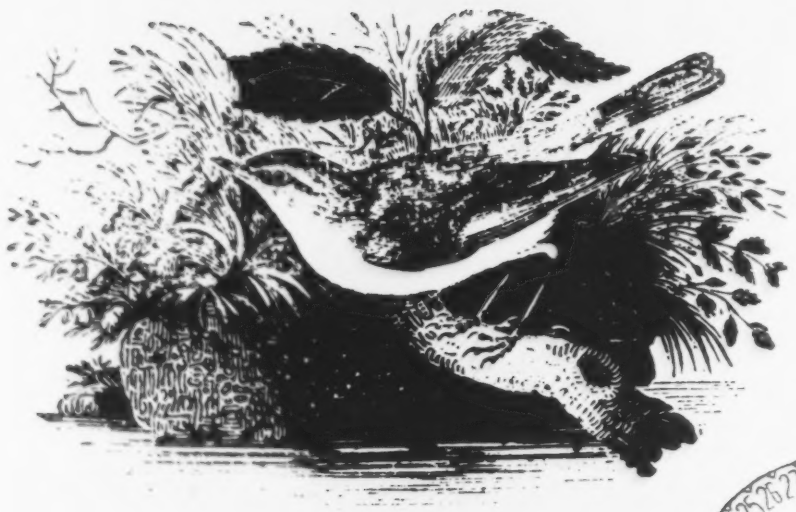
The ERIC Facility has assigned this document for processing to:

In our judgment, this document is also of interest to the Clearinghouses noted to the right. Indexing should reflect their special points of view.

ED271274

PREVENTION OF MENTAL RETARDATION IN RURAL AMERICA

SEPTEMBER 1984



"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Doris Helge

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

JUN 1986
RECEIVED
ERIC/CRESS

Doris Helge, Ph.D.
Executive Director
American Council on Rural Special Education
(Acres)
Western Washington University
Bellingham, WA 98225

RC015836

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

X This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

BEST COPY AVAILABLE

PREVENTION OF MENTAL RETARDATION

IN RURAL AREAS

(This document was extracted from
a 1984 presentation to the President's
Commission on Mental Retardation.)

August, 1984

Doris Helge, Ph.D.
Executive Director
American Council on Rural Special Education (ACRES)
Western Washington University
Bellingham, WA 98225
(206) 676-3000

©

PREVENTION OF MENTAL RETARDATION

IN RURAL AREAS

I. PURPOSE

This presentation described cardinal principles involved in the prevention of mental retardation in rural America. Relevant findings of national research conducted by the National Rural Project and the American Council on Rural Special Education (ACRES) from 1978-84 were summarized. Related work of the ACRES Futures Task Force and the National Rural Education Research Consortium were also shared.

II. SYNOPSIS OF FORMAL PAPER

The fact that many leaders in the field estimate that 90% of all mental retardation is caused by social-familial factors is especially significant when planning approaches for prevention in rural areas. The fact that the ratio of poverty is significantly higher in rural than non-rural areas emphasizes the predominance of social-familial retardation (mild retardation occuring predominately among those of low socio-economic status) across rural America. In fact, 60% or more of many rural school populations can be considered educationally disadvantaged by EASA Title I criteria. Mental retardation is also more prevalent in rural areas because of inadequate prenatal care and early intervention programs for other disabilities.

Serious ethical dilemmas of programming are related to the differences between the values of many lower socio-economic rural populations, such as migrants and Native Americans, and the values of rural middle class populations. Differences include divergent needs for achievement, expectations for success in life, and child rearing practices (particularly sensory and language).

Two major issues related to prevention of mental retardation in rural areas include (1) prevention-oriented programs are often not available, and (2) programs that are available are frequently not understood, valued, or used.

Table I below relates some of the causes of mental retardation and well-established preventive methods to facets of rural communities which frequently impede the implementation of preventive approaches.

RURAL FACTORS WHICH INHIBIT PREVENTIVE APPROACHES

TABLE I.

CAUSES OF MENTAL RETARDATION	PREVENTIVE APPROACHES	RURAL FACTORS INHIBITING IMPLEMENTATION
Genetic abnormality/ deficiency.	Genetic counseling and screening. Diagnosis to detect fetal abnormalities (e.g., amniocentesis).	Counseling and screening must not only be available but understood and valued by potential user's culture or services will not be used.
Immunizations not administered.	Immunizations readily available and systematically given, as needed.	Importance of immunization unknown to many rural citizens, especially many lower socioeconomic and transient populations. Systematic immunization programs often not available. Insufficient "tracking" systems for migrant populations. Some religious and other cultural groups are opposed to immunizations.
Inadequate spacing of children. Children born to parents who are too young to bear children who develop normally.	Educate potential parents regarding possible dangers to children and mother of inadequate spacing between children and of mothers giving birth at too early an age. Educate women regarding birth control.	Birth control viewed as a taboo subject in some rural subcultures, particularly when discussed with teenage girls. Early and frequent births are expected in many rural subcultures.
Birth complications/ need for early intervention with "at risk" infants.	Provide screening and intervention programs for newborn infants (e.g., low birth and "at risk" babies).	Families may resent "interference" with a "personal" family matter. Women having children at home and in some small hospitals do not have access to such programs. Screening and intervention programs must be readily available, understood, requested, and used.

BEST COPY AVAILABLE

TABLE I.
(Continued)

CAUSES OF MENTAL RETARDATION	PREVENTIVE APPROACHES	RURAL FACTORS INHIBITING IMPLEMENTATION
Inadequate intellectual stimulation.	Parent education regarding the importance of intellectual stimulation for normal development. Home teaching programs for infants and toddlers. Parent preparation for school drop-outs and other young parents. Parent education regarding what is normal development; essential interventions when development is not normal.	Many parents do not know what "normal" development is, have culturally established very low expectations for their children, or are not capable of providing intellectual stimulation. Home teaching for infants and toddlers and parent preparation programs are rare.
Abnormal physical growth and development. Unhealthy living conditions.	Parent education relating to normal development. Programs to provide assistance when nutrition is inadequate. Availability of quality medical care and regular check-ups.	Disproportionately high rates of rural poverty are related to inadequate diets and development and to unhealthy environmental conditions. Parents are frequently ignorant concerning dangers of peeling paint and other bases of lead poisoning. Nutrition education, WIC (Women Infant and Children nutrition program), and other programs are frequently inadequate. Rural values such as a fierce sense of independence negate the participation of many rural citizens in programs such as WIC. Due to poverty, ignorance, etc., many rural children do not see a physician until school age. Migrant tracking systems regarding health care are frequently inadequate or not used.

BEST COPY AVAILABLE

TABLE I.
(Continued)

CAUSES OF MENTAL RETARDATION	PREVENTIVE APPROACHES	RURAL FACTORS INHIBITING IMPLEMENTATION
Inadequate child care. Unstable family environments (e.g., emotional difficulties as with many transient families).	Parent education programs. Day Care services readily available. Parent training for parents who are themselves mentally retarded. Family counseling services available. Quality protective service workers and programs. Equal opportunities for minorities/migrants (to help relieve family stress). Respite care programs.	Parent education programs and day care services are frequently nonexistent. Parent education training for mentally retarded parents is extremely rare in rural areas. Family counseling services are rare in very remote areas. Many rural subcultures do not believe in involving "outsiders" in their personal problems. Protective services workers frequently do not travel to rural communities. Respite care programs are rare. All of the above are exacerbated in the case of migrant populations.
Functional retardation associated with a primary handicap or with more severe retardation because of inadequate "mainstream" stimulation or other educational opportunities. Functional illiteracy.	Early identification of a disability that could contribute to functional retardation if early and effective intervention does not occur (e.g., hearing deficiency). Integrated community contact programs (e.g., vocational training in the community to prevent greater effects of retardation). Appropriate educational programs.	Mild and moderate disabilities are frequently unidentified due to lack of appropriate screening programs, the relative ease with which the mildly and moderately disabled are accepted into rural life, and the rural value of "taking care of one's own." Early intervention programs are rare, particularly those involving infants and toddlers. Parent training for follow-through of such intervention programs is also rare.

BEST COPY AVAILABLE

There are six cardinal principles involved in a systemic approach of preventing mental retardation in rural areas. These principles include: (A) the recognition of the diverse rural subcultures existent in rural America, (B) the design of programs and approaches which consider the values and needs of local rural subcultures, (C) the recognition and use of local communication and power structures, (C) the optimal use of inherent positive attributes in a particular rural community, (E) transforming negative attributes into facilitating factors and (F) initiating interagency collaboration in ways realistic for rural service agencies. Implementation of each of these basic principles will be described below and related to factors in Table I above.

A. Recognition of Diverse Rural Subcultures

Rural communities are extremely diverse and vary from the homogeneous, very isolated "hollers" of Appalachia or Native American villages of Alaska to communities populated by transient migrant populations and those with proportionately large groups of cultural minorities. Local economies range from classic stable farm communities and small industrial towns to "boom or bust" resort communities or communities whose income is based on transient extraction industries.

The local economy typically has tremendous effects on the lifestyle of the community. In fact, some educational programs are cancelled or placed in a very low priority position during peak harvesting, hunting, or resort seasons.

Thus, "what works" is highly individualized from one rural community to the next. Having citizens involved in the local volunteer fire department distribute leaflets regarding the dangers of the lead content of paint peeling from deteriorating buildings or having trusted county extension agency "home visitors" describe the importance of appropri-

BEST COPY AVAILABLE

ately spacing children or stress the benefits of genetic counseling may be effective strategies in a variety of rural communities. However, even these fairly generalizable strategies must be appropriately individualized when difficult terrain, climatic impediments, or divergent religious beliefs dictate alternate strategies.

B. Design of Programs and Approaches Which Consider the Values and Needs of Local Rural Subcultures

Because of the diversity of "rural," programs designed to prevent mental retardation must be individualized for specific subcultures. Before designing such approaches, it is helpful to consider several fairly generic principles about rural communities. Generic principles that are related to the theme of this paper are described below:

1. Approaches advocating cooperation among citizenry are usually valued more than competetive approaches.

2. Relatively large families are generally valued (and sometimes expected), particularly among some rural ethnic minority and migrant populations.

3. Early marriages and relatively young pregnancies are usually viewed as normal.

4. Motivations for academic achievement are frequently lower than in non-rural communities.

5. Rural communities typically "take care of their own," and individuals with mild and moderate mental retardaton tend to fit into the mainstream of rural society relatively easily. These individuals are often less apt to be viewed as disabled.

6. Traditional methods of meeting educational and human service needs are usually valued much more than "innovative programs." Traditional institutions such as schools and medical agencies are also generally well respected.

6. The opinions of families and neighbors are trusted more than are those of medical and educational institutional personnel.

7. In rural areas which traditionally have been geographically isolated, "inbreeding" or close marriages are usually socially acceptable.

BEST COPY AVAILABLE

8. Incest is frequently not reported, partly because one must "live with one's neighbor" on a daily basis.

Rural traditions also include "neighbors helping neighbors," a "sense of community," a penchant for "self help," and a spirit of a fierce independence." Such characteristics and traditions can be helpful or problematic to program planners. For example, citizens may assume that each individual or family will not only privately make decisions regarding birth control and spacing of children but will also be able to independently solve problems regarding long-term care of an adult with profound mental retardation. In reality, the nuclear and extended families of citizens with retardation are frequently isolated from support organizations, information, and programs (e.g., genetic counseling, respite care, etc.) common in non-rural areas.

Factors that motivate rural citizens to assist with the prevention of retardation are largely intrinsic in nature. In fact, "outside interference" or external governmental mandates are frequently viewed not only as disincentives for change but intrusion to be "outwaited." Such "interference" might include advice from well-intentioned outsiders regarding the number or spacing of children, interventions suggested for "at risk" infants, or mandatory immunizations. More effective approaches include involving the local power structure (often called the "good old boys" network) in program design, fostering local ownership and indigenous leadership, and focusing on cooperative ventures. Successful strategies also frequently have a family orientation, involve volunteering, and provide social opportunities while accomplishing program objectives.

BEST COPY AVAILABLE

It is also sometimes necessary for professionals to re-define "functional mental retardation" according to the local rural culture. For example, many Native American populations in Alaska have been characterized as unmotivated non-achievers and daydreamers who are retarded. In reality, many of these individuals have been following the centuries-old tenets of their ancestors (e.g., focusing on nature and its phenomena, resistance to planning for the future, or stoicism) which for centuries have been functional for their struggle for survival and focus on self sufficiency.

C. The Recognition and Use of Local Communication and Power Structures

Adherence to this principle is paramount to program success. It is a sound investment of the planner's time to thoroughly assess local communication and power structurse. The individuals involved are seldom the same as those represented in formal organizational charts or descriptions of information dissemination systems.

Not only are local communication and power structures typically more efficient than those that are externally induced, but their leaders can inhibit program success if they are not integrally involved. Examples of successful employment of this principle follow.

1. Use of Informal Communication Systems

> Rural communities typically function better via informal vs. formal systems. The spoken word is frequently considered adequate (and often more valuable) than the written word. Trust is usually reserved for those who are native to the community (vs. those espousing unfamiliar ideas concerned with intellectual stimulation, genetic counseling, pre-natal nutrition, etc.). Informal rural communication systems or "grapevines" are highly efficient and usually superior to formalized information systems. They must be tapped extensively.

2. Involvement of Indigenous Local Leadership

BEST COPY AVAILABLE

If possible, planners should arrange for program ideas to be generated from local citizens and indigenous leaders whose support is imperative for the implementation of preventive approaches. Ideas should at least be disseminated by local leaders. Indigenous leaders to whom the community looks for guidance or approval should be involved in program development. If this does not guarantee their approval of "foreign" ideas, steps should be taken to ameliorate their concerns. As a last resort, they should be put in a position where they will not "kill" an essential program. (E.g., have them visibly support another part of the total program -- preferably a related or inseparable component.)

3. Recognition and Use of Existing Communication Vehicles.

Personnel of established rural-oriented outreach systems which involve visiting with citizens while delivering information and services are generally trusted and valued. These include county extension workers, bookmobile and other outreach employees of local libraries, mail carriers, and members of some local churches and civic clubs. Such employees and trusted community members who are reinforced for visiting with citizens and disseminating information can effectively promote preventive approaches. They can be used to convince citizens of the potential usefulness of diagnosis to detect fetal abnormalities to educate rural parents regarding the environmental causes of mental retardation, and to educate pregnant women regarding the superiority of breast feeding.

4. Involve Families in Programs, Including Siblings and Extended Family Members

Teen-tot-family clinics can promulgate ideas that are relatively alien to the local culture (e.g., needs for and concepts of structured intellectual stimulation programs). Trained extended family members can describe the health consequences of early pregnancy. They can also stress that it is to the entire family's advantage to adequately space children and to secure sufficient fiscal resources before having children. Local trusted family members or community leaders are not viewed as attempting to influence people not to have children but as being thoughtful regarding the welfare of the total family. They are sometimes the only persons who can sanction the use of public services.

5. Involvement of Neighbors with Similar Concerns

Parent support groups are still fairly unusual in rural America, particularly in remote, isolated areas. Yet contacts among families having children with mental retardation are extremely helpful in promoting realistic guidelines for measuring success.

BEST COPY AVAILABLE

The "parent to parent" program concept is especially beneficial as it fosters a sense of equality and sharing among parents with common problems and concerns. Such programs are best generated by family members (vs. professionals). A public service announcement via the local radio station which describes the name and home telephone number of an indigenous leader is more likely to receive calls for membership in the group than is an appeal by an agency.

In the rare instances when there is more than one parent group in the rural area (e.g., one group concerned with toddlers and one with school-aged children), it is beneficial for the groups to meet together occasionally. This provides some continuity for an emphasis on intellectual and other stimulation to prevent secondary handicaps or functional retardation.

6. Involvement of Local Physicians

Physicians should be educated regarding the needs and concerns of parents. It is also important that physicians also understand family resurces available to them so that parents can be used to support each other. For example, a particularly helpful approach to both parents and medical personnel is for physicians to have a list of parents who can be available to speak with or be called by parents who hear for the first time of a diagnosis of retardation or a related problem.

7. Use of Local School Personnel

Schools should educate students (who are sometimes the best communicators with rural parents) regarding infant stimulation procedures, principles of nutrition, the importance of healthy living conditions, etc. Home economics and vocational educational classes should be engaged in special projects regarding normalization activities, provision of intellectual stimulation, etc. Such activities could involve academic credit, as appropriate.

D. The Optimal Use of Inherent Positive Attributes in a Particular Rural Community

The "sense of community" in rural areas, less hurried lifestyles, and less available social opportunities, contribute to increased interest in volunteering to help one's neighbor. The needs for local identification of problems and the highly efficient "grapevine" communication

BEST COPY AVAILABLE

systems (both described above) can be used to contribute to local design and ownership of methods to prevent mental retardation.

The need for "news" for local newspapers is a prime opening for a prevention-oriented professionals and family members to informally get to know the newspaper editor and educate that individual regarding appropriate prevention articles. These could stress concepts such as available screening and intervention programs, nutrition education, the superiority of breast feeding and the need to adequately space children, and the dangers of peeling paint on dilapidated buildings, etc.

The task of the planner is to identify all potential positive community attributes that can be used to facilitate preventive approaches. For example the fact that rural school personnel enjoy a level of respect not found in urban settings means that school personnel can also successfully counsel students about the benefits of delaying pregnancy.

E. Transforming Negative Community Attributes into Facilitating Factors

Many rural community characteristics that are initially deemed negative can become positive attributes. A basic tenet in accomplishing the shift of negative to positive is the use of the well-respected and efficient informal systems of the community. Thus, involvement of family, church, and other social ties is essential. For example, a majority of rural communities have disproportionate numbers of retired and other senior citizens who may not support new programs focusing on prevention. Typically educating such citizens and involving them in prevention programs (as foster grandparents, extended family counselors, resources to the county extension efforts, or in other capacities

BEST COPY AVAILABLE

described above) creates a more positive community attitude towards programs. In fact, many older citizens are "prime movers" of the community's communication system.

F. Initiating Interagency Collaboration in Ways Realistic for Rural Service Agencies

Unique principles of interagency collaboration are essential for successful implementation of preventive approaches. Such collaboration is conducted uniquely in rural areas because agencies are more scarce and typically more generic in scope. Long distances between agencies and scattered client populations also inhibit interagency staff meetings.

Typically, interdependency exists between general health and social welfare agencies and between schools and disability agencies such as vocational rehabilitation, developmental disabilities, and vocational education. The importance of involving unique rural agencies and models, such as the county extension system, and of involving local physicians, cannot be overestimated. It is also essential that families (including extended family members and siblings) and local citizens be informed and involved. National resources such as the migrant health tracking systems should be forced to be accountable to rural communities.

III. SUMMARIZATION STATEMENT

High rates of poverty and other attributes of rural settings contribute to disproportionate ratios of mental retardation in rural America. Prevention-oriented programs are often not available or fully used. The paper has described six approaches which are essential when tailoring traditional preventive approaches for rural settings.

BEST COPY AVAILABLE

All preventive approaches take time for their effects to be felt. For example, there is a 5-year lag between pre-natal care and its influence on children in school. Prevention program personnel who were not reared in rural areas will probably experience significant frustration with their perceptions of how slowly new approaches are adopted. The consolation is that when new strategies are adopted, the efforts are sincere and become an integral part of community functioning.

IV. RESOURCES FOR ADDITIONAL INFORMATION FOCUSED ON RURAL CITIZENS WITH DISABILITIES

The American Council on Rural Special Education (ACRES) is a national membership organization that manages task forces organized to link rural parents and professionals with resources. ACRES also offers computer searches and publications on relevant topics, hosts an annual national conference for those interested in enhancing services for rural individuals with disabilities, manages a rural electronic bulletin board, and provides other services. For further information, contact: The American Council on Rural Special Education (ACRES), Western Washington University, Bellingham, WA 98225; (206) 676-3000.

The National Rural Research Consortium offers opportunities for rural practitioners and researchers to cooperatively conduct research related to enhancement of services for rural citizens with disabilities. For further information, contact: The National Rural Research Consortium, Western Washington University, Bellingham, WA 98225; (206) 676-3000.

BEST COPY AVAILABLE